



# A MAP OF SERVICES FOR PEOPLE WITH SIGHT LOSS IN WALES

**Authors:** Richard Bowers, Owen Williams

Wales Council of the Blind  
Funded by Thomas Pocklington Trust

October 2023

**Contact:** Wales Council of the Blind, Unit 3.1, Hastings House, off Fitzalan Road, Cardiff CF24 0BL.  
029 20 473 954  
[wcb-ccd.org.uk/perspectif](http://wcb-ccd.org.uk/perspectif)  
[richard@wcb-ccd.org.uk](mailto:richard@wcb-ccd.org.uk)

## **CONTENTS**

<u>PREFACE</u>	<u>3</u>
<u>PREAMBLE</u>	<u>4</u>
About Perspectif	4
About the geography of Wales	5
About the categories	8
<u>SIGNPOSTING: THREE KEY ROLES</u>	<u>10</u>
Role 1: Vision Rehabilitation Specialists (VRSs)	10
Role 2: Eye Clinic Liaison Officers (ECLOs)	15
Role 3: Low Vision Service Wales (LVSW)	18
<u>WHAT SUPPORT IS OUT THERE?</u>	<u>24</u>
<u>CASE STUDIES</u>	<u>34</u>
<u>GENERAL CONCLUSIONS AND RECOMMENDATIONS</u>	<u>40</u>

## **PREFACE.**

This report was funded by Thomas Pocklington Trust, a leading charity that strives for equality of blind and partially sighted people and people affected by sight loss, in every aspect of society. With the growth of social prescribing as a concept in health and wellbeing, it is timely that an overview of available services is carried out so that informed decisions can be made by professionals when signposting people with sight loss into support in their communities. The online database, *Perspectif*, goes a long way towards achieving this aim. This report is as much about the database as it is about the services themselves and shows the importance of self-evaluation when carrying out our work.

Providing people with information, advice and support post diagnosis is critical to enable people to understand and accept their condition and live independently in the way they choose. In the recently launched 'Eye Care Support Pathway' report, the *Perspectif* database was highlighted as an example of good practice in the 'Support after diagnosis' section. This is because it enables a quick way to obtain customised information for patients and can also service as a tool for social prescribing. We hope that the database and mapping leads to improved outcomes for people affected by sight loss in Wales and provides a useful blueprint for other parts of the UK.

- Charles Colquhoun  
Chief Executive, Thomas Pocklington Trust

## **PREAMBLE.**

This report sets out to give a picture of the services and support provided by the third sector for people with sight loss in Wales. It first takes a look into **three roles** that play a key part in directing people to third sector support: the Vision Rehabilitation Specialist; the Eye Clinic Liaison Officer; and the Low Vision Service Wales practitioner.

It then considers in general **what support is out there** for people with sight loss in Wales. To do so, our online portal Perspectif was used as it contains the largest database of services for this specific group of people.

Thirdly, it presents a hypothetical **case study from 9 locations** to examine what support is available to fictional individuals living in specific parts of Wales.

### About Perspectif.

Perspectif has no fixed boundaries: it includes services from all sectors and covers everything from a VI Club to Welsh Government services such as the Low Vision Service. It is structured around the support on offer with the service providers sitting in the background. All **services** have a **provider**, and a provider may have any number of services to offer.

The database has recently been overhauled both structurally and in terms of functionality. Its records have been checked in batches over the last year and these checks are ongoing. They are conducted by WCB staff and volunteers on the one hand, and by occasional calls to the service providers to check their own records for accuracy. Registered users are now able to report errors and updates directly from the web page. This gives all providers the opportunity to feed us with corrections and updates.

WCB has been recognised by the Wales Vision Forum as the best organisation to serve as a single point-of-access for the sector. Perspectif is an important ingredient in delivering this role.

About the geography of Wales.

Perspectif allocates each service to any number of the 22 current local authorities of Wales. Other geographical groupings have emerged – smaller ones such as the Primary Care Clusters, and larger ones such as the Local Health Board areas. The former is much harder to base a national database on, and the latter is too broad as too many services would not cover an entire Health Board. Also, in recent times the most stable geographical boundaries have been the local authority areas, so Perspectif remains aligned to these.

In broad terms, Wales is broken down into a mixture of historical and current local authority boundaries that result in the various territories of the local societies for blind people. For example in Gwent, which is now a group of local authorities in the South East of Wales, one organisation operates over that area largely for historical reasons. Similarly, the old county of Radnorshire provides the boundary for a society based in the middle of Powys while in the south another society names itself after the historical county of Breconshire. (The old county of Montgomeryshire in the north of Powys is not served by a local society). In this case the choice is pragmatic since Powys is a physically large local authority which, even at a local authority administrative level, is still broken down into three smaller areas: North, Mid and South.

The rurality of Wales ought to have a significant impact on the availability of services. Given that the largest conurbations are clustered along the north and south coastal areas one would infer that people are poorly served in the central rural regions, particularly as that is where our Regional Societies are based. And along the eastern border with England, the likelihood is that people close to the border would make use of the larger towns and cities in England such as Hereford and Shrewsbury. For this reason, Perspectif is not restricted to services in Wales – along with UK-wide services it will also pick up some that are situated along the border, although these have not been identified systematically.

The Welsh Index of Multiple Deprivation (<https://wimd.gov.wales>) gives information about the relative availability of services generally in each part of Wales. We used this data to choose the areas for the service-user survey, and to establish a level of expectation in our results from postcode searches in Perspectif. Our thinking is that there should be a rough match between the access to services generally and those for people with sight loss, in each area.

Other national data we looked at in relation to a set of postcodes were the drive times to the nearest settlement of 10,000 or more. A Statistical Focus on Rural Wales (2008) maps the parts of Wales that have a drive time of at least 20 and 40 minutes to the centre of the nearest such settlement. Also provided in this document is the map of domestic residences on a hectare-by-hectare basis. So, these three representations of data were used together to inform our conclusions about service coverage in Wales.

For the purposes of comparison, we identified nine postcodes in Wales according to the broad geographical regions of north, mid and south Wales. (Table 1). In each of the three regions we identified three postcodes corresponding to 40 minute, 20 minute and zero minute drives to the centre of the nearest settlement of 10,000 persons or more.

For each postcode, we looked up the Welsh Index of Multiple Deprivation ranking for Access to Services. There are 1909 WIMD areas in Wales, and each is ranked according to various domains such as health, housing, income and so on. We looked at the domain **Access to Services** in order to make a comparison with services to people with sight loss as identified by Perspectif. The areas were chosen to give rankings in three broad bands: 0-100, 101-1000, 1001-1909.

The postcodes were used in the searches on Perspectif. The ranking for Access to Services is lowest (poorest) to highest (best). A ranking (overall) using a similar scale is given representing all domains ('Overall').

These results are given in the following table. In this table the Perspectif values are the service counts resulting from a plain search by Local Authority with LWSW optometrists removed.

**Table 1: Access to services by postcode**

		0 mins	20 mins	40 mins
North	Area	Offa	Llansanffraid	Llansannan
	Access to services	1047	381	25
	Overall	717	1500	1001
	Postcode	LL13 7RH	LL28 5TG	LL16 5HG
	LA	Wrexham	Conwy	Conwy
	Perspectif count (for LA)	30	37	37
Mid	Area	Llanbadarn Fawr North	Rhiwcynon	Llandloes 1
	Access to services	319	52	1577
	Overall	1689	1304	1532
	Postcode	SY23 3AR	SY16 3EL	SY18 6DX
	LA	Ceredigion	Powys	Powys
	Perspectif count	21	21	21
South	Area	Adamsdown 2	Cowbridge 1	Lampeter Velfrey
	Access to services	349	1834	78
	Overall	361	1768	1289
	Postcode	CF24 0BL	CF71 7AF	SA67 8UH
	LA	Cardiff	Vale of Glamorgan	Pembrokeshire
	Perspectif count	34	27	20

(NB The source of the data for the drive times (A Statistical Focus on Rural Wales 2008) doesn't identify *which* settlement is the nearest.)

We can derive from this data that there is no direct correlation between drive times and Access to Services rankings. Nor is there between Access to Services and Overall rankings. In general it indicates that the situation in Wales is not a simple correlation between proximity to conurbations and availability of services.

With regard to services yielded through Perspectif, there does appear to be a notable depletion across Mid Wales, which correlates with our expectations.

### About the categories.

We felt that we should allocate the Perspectif categories to the closest matching ones proposed by Visionary in order that comparisons might be made in the future. To do this we went through each service within a Perspectif category and allocated it to the closest matching Visionary category (see Table 4.1). Furthermore, in the case study findings we indicated which sector each service was provided within (or, more specifically, the sector to which the service *provider* belongs). This enabled us to consider services offered by, for example, the private sector so that we can see where gaps might be being filled outside the third sector. An example is Wales' Low Vision Service which, unlike in England, is a public sector service delivered by high street optometrists as part of the Wales Eye Care Service. An equivalent service in England might be provided by a Local Society in a Resource Centre. If we were to exclude this public sector service from this study, it would appear as if there was no low vision service available in Wales.

There are a number of Visionary categories that do not exist in Perspectif and vice versa. Categories are not an exact science and can be rather subjective. We understand that the Visionary categories were decided by a consensus of opinion. Perspectif's categories were developed by one person in the first instance and have been modified since. Indeed, they need not be fixed and can be added to. The aim in Perspectif is to have a balance between a list of categories small enough to be manageable but sufficient in number to make meaningful distinctions. A workaround to this problem – since Perspectif is structured to allow only one category of service for each record – was to develop a keyword system to assign multiple categories to any one record. This was not adopted in this survey as it has not been fully implemented yet.

Another problem arises with what one might call 'blurred' categories. Training is one of these. Perspectif uses 'training' to cover not only Visual Awareness Training (Visionary's more specialised category), but also computer/digital skills training, the Living With Sight Loss courses and so on. Also, clearly a distinction ought to be made between training



for people *with* sight loss and training for those *working with* people with sight loss. For the purposes of this study, Training services have been split and allocated to the Visionary categories eg. a digital skills programme would fall under Technology Services.

Another 'blurred' category is Perspectif's 'Sports, Arts, Leisure and Holidays'. There is no doubt that there's a possible overlap between these concepts, so it seemed reasonable to merge them in order to reduce the number of categories. Also, it seems that Social Activities (Visionary) must have taken into account the overlap with Sport, but without seeing the actual services that fall into the Visionary categories, it's difficult to assess this. For the present purpose 'Social Activities' has been aligned with Perspectif's 'Clubs and Social Groups.'

## **SIGNPOSTING – THREE KEY ROLES**

We have identified three **key workers** in the health and social care sectors who are well placed to signpost individuals to support in the community (mostly third sector), being workers who are connected directly to people with sight loss. These are the Vision Rehabilitation Specialist (VRS – formerly known as ROVIs); Eye Clinic Liaison Officers (ECLOs); and Low Vision Service Wales (LVSW) practitioners in optometry. This section looks at the roles these workers play in forming pathways to services.

### **Role 1: Vision Rehabilitation Specialists (VRSs)**

VRSs are aware of a spectrum of third sector support and do refer people onwards where necessary. However, these referrals are generally informal, making it difficult to monitor for analysis purposes. There are variations and gaps in third sector provision with some strong areas and some that are less so, and the VRS is sometimes faced with not having any services locally into which to refer people. They might also make their own assessment of the usefulness of the support:

*“Do not refer to the local blind society. People say there’s no point as it doesn’t interest them.”*

The referrals sometimes go *from* the third sector *to* VRSs:

*“The local group signposts people to us – they help with peer support and referral pathways.”*

Where the VRS has stronger links with the local society, there are positive outcomes arising from the VRS getting directly involved with the service users through the group. For example, the VRS can talk to groups of service users to remind them of daily living skills to aid their independence. This approach both maximizes contact with service users and increases wellbeing through social contact. This latter is a valuable role that the third sector is best placed to deliver, and the VRS can enjoy a captive audience to offer advice.

However, VRSs in some areas are finding gaps in direct service delivery such as face-to-face counselling, digital technology support, and welfare benefits advice.

*“There is a gap in provision since RNIB’s Online Today and welfare benefits service in Wales have come to an end.”*

These services were highly valued and their termination has nothing to do with demand – it’s simply a matter of sustainable funding not being available. But the instability of third sector provision may make VRSs disinclined to send their clients to third sector support.

Also, where services do exist, they may not be delivered in a way that is appropriate for all clients. One VRS commented:

*“Counselling is an issue – RNIB is only doing telephone counselling and it’s over-subscribed. There needs to be face-to-face counselling as well.”*

Similarly, some digital technology support is only given online or by telephone, and sometime only supporting a narrow range of products. What is needed here is a service that covers the full range of access technologies that is delivered in a hands-on setting. VRSs are asking for digital technology training because they have few third sector support services to refer clients to. While information technology falls under one of their competencies (communication), the VRS cannot be expected to be supporting individuals at a detailed level. Indeed, some VRSs are unable to support in this field and some do not wish to as they don’t see it as part of their remit.

The third sector is well positioned to deliver such support given the right funding, as evidenced by the better-resourced regional societies in Wales. Also, charities may have access to volunteers to carry out this kind of work, but this is a fragile arrangement, depending upon the good will of a very small number of people. While there are obvious cost benefits to using volunteer-driven support, there should be no expectation of their sustainability as they are often very individually tailored programmes of work. For example, Ceredigion Association’s volunteer-led digital technology support it considered a lifeline by the VRS there, but it is very much dependent on a single volunteer who would need to retire at some point. This is not meant in any way to denigrate the work of volunteers. Rather, it is to draw attention to the risks associated with placing the onus on the third sector when there is often insufficient funding coming in at a sustained level.

Managing Better, a sensory loss service currently provided by Care and Repair Cymru, is popular with VRSs and this is an example of a good relationship between the VRS and the third sector. This is an all-Wales service and is delivered consistently across the country.

In some areas, the VRS refers people to organisations not situated in their local authority. In these cases, the individual may be missing out on a more convenient service, local to them. Whilst we recognize that services are offered by more than one organization, it is unhelpful to ignore the options that might be more convenient to the service user. This situation can arise when a VRS is procured from a third sector organization that only offers services outside the local authority area the VRS works in. One organization reports that they never receive referrals from the VRS in their area. In other areas, the third sector organisations that employ VRSs only within their areas of coverage have developed strong and effective referral pathways into their third sector support, as one might expect.

### **Data on Vision Rehabilitation Specialists collected summer 2022.**

The rehabilitation support available to the theoretical service users would be delivered by the local authorities below. We gathered information from each of these on the waiting times\* and capacity to serve as a reminder of how referrals to the third sector should be encouraged sooner rather than later and that the group of three signposting agencies should independently make referrals to avoid delays. It is generally understood that early interventions are important in preventing the adverse effects of sight loss in areas such as employment, general health and wellbeing, social isolation and so on. There should be no reason why third sector support be withheld until a rehabilitation worker is available. Some people report that the first person they get help from is a VRS and a waiting time of 5-19 months is far too long for no action to be taken when the person is in need of financial support, help with maintaining employment, emotional support and so on.

(\*Waiting times are calculated as being from receipt of a referral (via the CVI, from LVSU or self-referral) to the point of the VRS assessment.)

**Table 2: Waiting times to receive a rehabilitation assessment in the 7 local authorities serving the sample postcodes.**

<b>Wrexham</b>	<b>16 months.</b>	2 FTE VRSs	Referrals on the waiting list are reviewed periodically and citizens contacted periodically also. With a population of 135,957, Wrexham meets the minimum standard of 1 VRS per 70,000 of the population.
<b>Conwy</b>	<b>5 months</b> for non-urgent referrals	1 FTE VRS and 1 trainee.	With a population of 117,203, Conwy does not meet the minimum standard of 1 VRS per 70,000. However, the trainee VRS can support the VRS, and additional support is provided by a senior VRS covering 3 LAs in North Wales, when needed.
<b>Ceredigion</b>	<b>7-weeks</b>	1 FTE VRS and 1 assistant (not a qualified VRS).	With a population of 72,695, Ceredigion meets the minimum standard of 1:70,000.
<b>Powys</b>	<b>12-months</b> for non-urgent cases	3.5 FTE VRS	Powys, the largest authority, is an example of good practice in Wales. Their waiting list has fallen as a result of additional VRSs.
<b>Cardiff</b>	<b>5-months</b>	1 FTE VRS	Cardiff is the most underserved authority in Wales linked to population (366,903).

			There are concerns around internal referral pathways.
<b>Vale of Glamorgan</b>	<b>No data</b>	1 FTE VRS	With a population of 133,587, the Vale falls below the minimum standard of 1:70,000.
<b>Pembrokeshire</b>	<b>No data</b>	2 FTE VRSs.	With a population of 125,818 it meets the minimum standard of 1:70,000.

This variable speed of delivery for rehabilitation support across Wales only serves to highlight the importance of Third Sector support of kinds that do not interfere with the key VRS interventions - chiefly mobility and daily living skills. Other needs can be served by the third sector, and to do so would make a significant contribution to ensuring the individual is not left unsupported for long while waiting for the rehabilitation work to begin. Where VRS workers themselves are supplied by local societies under contract – as is the case in a number of areas in the north and south of Wales – there is a strong likelihood of an early referral into the local society for additional support. However, these are also the areas that have strong local societies in the first instance, probably as a result of their population densities. However, the table shows that it is not enough to have a strong third sector presence alone in the area – the minimum standard (1 VRS per 70,000 population) should still be met in order to deliver effective rehabilitation.

Rurality has to be considered, particularly in areas where there is no third sector presence, and it could be argued that the ratio of VRSs to population is insufficient in dealing with a county such as Ceredigion. During Covid and for some time after, some VRSs were conducting telephone assessments over the phone – because this was better than no service. Now that face-to-face assessments have returned, the waiting lists and times have greatly increased. In Ceredigion, when we collected the above statistics, 10 people were on the waiting list for an assessment. At the beginning of October 2023 there are now 39 on the waiting list with the VRS reporting a high case load. So, while the telephone assessments were reducing the waiting lists, the quality of the assessment is likely to have been hampered by the lack of first-hand awareness of the person’s living conditions. Also, there was a likelihood that cases would be closed prematurely because no mobility training

was being offered during the Covid restrictions. Needs were being left unmet due to these restrictions.

The problem of rurality can in part be dealt with through the use of mobile support such as that provided by Vision Support's Mobile Information Unit. With the cost-of-living crisis making travel difficult for people on low incomes or with mobility difficulties, it is onerous to have to visit the Resource Centres of the Regional Societies. A mobile service, well connected to the local VRS, offers considerable support to remotely situated people. Indeed, the mobile resource would be well-placed to work with the LVSW, perhaps offering demonstrations of low vision aids or advice in using them.

### **The VRS and Perspectif.**

WCB shall be giving Perspectif training to all VRSs in Wales. Because they are a defined user group in Perspectif, as are LVSW practitioners and ECLOs, we can obtain some statistics on the kinds of recommendations being made to service users. This will aid monitoring and evaluation. We would also like practitioners to tell us of services that are unavailable in their areas so that we can research alternatives and make them available on Perspectif.

### **Role 2: Eye Clinic Liaison Officers (ECLOs)**

ECLOs are included here because the majority in Wales are provided by third sector organisations and consequently form an important link to third sector support.

In the majority of cases there is a strong working relationship between the ECLO and the VRS. Referrals are made, sometimes via the Single Point of Access (SPoA) in the local authority, but, importantly, the ECLO will notify the VRS of having made a referral.

The VRS will also make inquiries to the ECLO occasionally:

*“ECLOs help with getting copies of CVIs and understanding eye conditions.”*

## **ECLO referrals to the Third Sector**

Given that the ECLOs in Wales are employed by four different organisations, three of which are third sector, it is likely that there will be differences between their services. It might be beneficial to conduct a survey, similar to the work done here with services generally, to establish the nature of the support given in each hospital, the ECLOs' training needs, and the information provided to patients. If there are found to be large differences of service, the survey could contribute to the establishment of minimum standards for a consistent service across Wales.

### **The geography.**

There is often a geographical mismatch between the hospital where the ECLO sees a patient, the Local Authority that would support the patient via a VRS, and the local society that covers their residential area. Hypothetically, a patient in Cardiff Heath Hospital, living in Caerphilly, would be seen by a VRS from Caerphilly County Borough Council, by a Supporting People officer from Sight Cymru covering the borough, yet might find access to Sight Life in Cardiff for aids and equipment easier than travelling to Sight Cymru in Blackwood. The ECLO must be aware of these distinctions to offer the best range of choice for the patient. VRSs generally report that this understanding is there and that they receive appropriate referrals:

*“There’s a good relationship with the ECLO who refers to social care through the duty team. If it’s an urgent case they let the VRSs know at the same time via email.”*

There is good ECLO coverage in Wales. Every Health Board has an ECLO (although some posts are currently vacant) – some are employed by the third sector and some by the health board itself.

### **Referrals from ECLOs to Social Care.**

VRSs receive referrals from Eye Clinic Liaison Officers. Broadly speaking, the ECLOs are referring patients to the appropriate rehabilitation team, sometimes via the Single Point of Access at the LA.



ECLOs are referring clients to the sensory teams through a variety of means and they are all aware of the role of the VRS. There have been instances where the VRS and the ECLO would share training days so that each other's roles are clarified. (One is scheduled for November 2023). This is a networking opportunity to discuss referrals. Sometimes there are misunderstandings:

*“We sometimes query the ECLO for benefits advice but it comes back. The ECLO says that the VRS will deal with that. Is this a VRS role? I am concerned about this as the client needs support with benefits.”*

(There has been a gap in benefits advice support since the ending of the RNIB's RAISE welfare benefits advice service – a problem with third sector reliance on short-term funding).

Periodically, networking opportunities would enable misunderstandings such as these to be ironed out between the ECLO and the VRS.

The relationship between ECLOs and VRSs is strong. While the direction of travel is generally from the ECLO to the VRS in the form of referrals, there are times when the VRS will contact the ECLO for information on eye conditions or simply to get a copy of a CVI.

*“There's a great relationship. We sometimes ask for info on patients to establish their place on the waiting list. The ECLO always helps us out.”*

*“There are some communication issues with ECLOs. Where they work closely with the VRS and Third Sector it makes a huge difference.”*

The VRSs and ECLOs should meet periodically to strengthen links, to reinforce their respective roles, and to coordinate their information provision for the benefit of the patient. They could also check that referrals are getting through and discuss waiting times.

It may be fruitful to conduct a survey into ECLO services to gain a better understanding of the referral pathways they favour and the regional differences. A survey might also look at ways of strengthening links

between health and social care and the third sector via the ECLO services. Little is known currently about the pattern of referrals from ECLOs into the third sector. Consequently, until a better understanding is gained, it's important to ensure the VRS (being the worker that ECLOs do refer to) builds strong links with a full range of third sector providers, not merely sight loss charities.

### **Role 3: Low Vision Service Wales (LVSU)**

#### **Pathways**

There are pathways between the Low Vision Service Wales and the Third Sector. Each LVSU practitioner completes a record card as part of their assessment of the client's needs. They also ask depression screening questions to trigger a referral into mental health support when appropriate. As part of their accreditation, practitioners are trained to identify the appropriate contacts in social care (notably the VRS) and in the third sector. To aid in this, practitioners are encouraged to use WCB's Perspectif database to identify sources of support for the patient. WCB has provided training on this as part of their accreditation cycle.

The relationship is reciprocal - VRSs refer clients to the service and LVSU practitioners refer their clients to the VRS where they have identified that there is a need. Third sector organisations are also likely to check if a person presenting to them has accessed the VRS and/or the LVSU practitioner. It is clear that the notion of a strict pathway is something of a misnomer - a network is the more useful model in actual practice, one that is responsive to local needs. The important thing is that each of these agencies is aware of each other and checks that their client or patient is aware of these sources of support.

WCB's Perspectif currently holds the only complete list online of LVSU specialists. It's available at <https://wcb-ccd.org.uk/perspectif/wales-eye-care-service>.

**Table 3:** Data provided by LVSW showing LVSW assessments carried out over the years 2018/19 – 2020/21:

Year	Total assessments	Re-ferrals into:	New patients		Follow-up patients		Total
2018/19	4182	Social Services	359	8%	445	8%	804
		Third Sector	706	16%	919	18%	1625
2019/20	8992	Social Services	321	8%	448	8%	769
		Third Sector	704	18%	915	18%	846
2020/21	5211	Social Services	209	8%	243	9%	452
		Third Sector	412	20%	437	16%	849

## **Returning to the service / Life-long support.**

Patients are entitled to an annual low vision assessment and are encouraged by LVSW practitioners to attend. This is recognised as a critical element in the service in the long-term support and enablement of independence of the person with a vision impairment. This annual assessment, apart from checking on vision and low vision aids, is an opportunity to look holistically at the patient's lifestyle and needs, prompting, where necessary, a review of the support the patient has received from social care and the third sector.

Since LVSW patients are encouraged to be seen on an annual basis there is an increased likelihood of their being referred into third sector services. We can see from Table 3 that a considerable number of referrals to the third sector occurred in subsequent years because it is likely, in the first assessment, the practitioner is more focused on information-gathering and vision rehabilitation than signposting.

With the new referral pathway being established between LVSW and the third sector via Perspectif, we must monitor the activity on this pathway and assess the impact on stretched third sector services. LVSW practitioners are able to review their previous signpostings through a folder system. At a higher level, the LVSW can be supplied with reports to show referrals with WCB's observations on the patterns.

## **Expansion of LVSW.**

As described in the 'Future Approach for Optometry Services', contract reform will enable all optometry practices in Wales (previously capped at 200 practitioners) to offer the low vision assessment. This would naturally increase the number of referrals into social care and the third sector. This reinforces the need to build a healthy third sector in order to address the likely growth in demand arising from these referrals.

An increase in LVSW practitioner numbers might increase referrals to WCB via Perspectif to point out gaps in services that are actually requested by patients. We shall try to monitor this. For example, a LVSW practitioner has requested information on sources of help (grants) to purchase a specialist piece of access technology demonstrated to a child and their family at a recent open day. The family and practitioner were unsure of support, and the equipment could not be provided through the LVSW scheme. As we raise awareness of the third sector

and subsequently digital solutions, we will find more and more people looking for grants. We shall develop this section of Perspetif.

Although the data reported in Table 3 show fairly consistent levels of referral across the three years on a Wales-wide basis, some individual VRSs report a drop in referrals from the LVSW.

This drop will have an impact on the level of third sector support being provided to LVSW patients, since the VRS has a significant role in making referrals to community-based support.

### **Domiciliary LVSW visits.**

Where home visits are offered for LVSW assessments, there is a greater chance that other factors in the home affecting the client will be apparent to the optometrist, thereby increasing the likelihood of a referral to the VRS where needed. Also, the need for domiciliary visits suggests limited mobility and a risk of social isolation on the part of the patient and thus, perhaps, limited access to third sector support. A referral made by an optometrist to the local society, for instance, might open up possibilities for the individual that could have gone unnoticed in their isolated state. A Domiciliary LVSW visit might identify support from the third sector either in the form of home visits or tele-befriending for example.

It's worth noting that many people with sight loss, who had the requisite digital and telephone access, felt less isolated during Covid due to the increase in online support through clubs and discussion groups. The flipside of this is that it has become harder for group organisers to get people to attend face-to-face meetings.

Therefore, the domiciliary service is another vital agency in linking people to support from the third sector, although we see that rurality impacts upon the timeframe necessary for the optometrist to complete an assessment when taking travel into account. Some optometrists are disincentivised from offering domiciliary visits in rural areas.

## **The Low Vision Assessment record card.**

The LVA record card offers signposting of the patient to third sector support.

CPD training for LVSWS practitioners serves as a reminder of their responsibility to refer clients to support in the third sector. It would be beneficial to maintain this awareness by issuing regular updates on Third Sector services in the form of a bulletin or directory. WCB shall do this using its Perspectif database. The bulletin will remind practitioners of the existence of Perspectif, and the benefits of third sector support.

It is productive when LVSWS practitioners work with third sector groups.

*"The LVSWS is an amazing service. Some opticians refer to third sector but some do not. Sight Life set up a Low Vision Support Group. Some practitioners embraced it as it meant that people kept using their magnifiers."*

*- Comment from Sight Life.*

Local and regional sight loss organisations, being well connected with service users, are ideally placed to offer ongoing support to LVSWS clients in such a manner. This would be best supported by the involvement of the optometrist, ensuring that patients continue to use their low vision aids effectively.

## **LVSWS and the CVI(W)**

An important development has occurred in Wales. The Certificate of Vision Impairment Wales (CVIW) may now be issued to patients with bi-lateral Dry AMD *from the high street*. Primary Care Optometrists, who hold dual Eye Health Examinations Wales and Low Vision Service Wales accreditation, may complete Certificates of Vision Impairment for patients with bi-lateral Dry (Atrophic) Age-Related Macular Degeneration who are resident in Wales.

This roll-out would see more people referred into the third sector that were previously hidden.

This new opportunity to be certificated provides the patient with an additional route into third sector support that is available on the high

street. Now that this is launched, it is important that third sector organisations are aware of this potential increase in referrals. Furthermore, given the ambition to increase the range of eye-conditions eligible under this high street referral route, the number of CVI referrals into the third sector will be set to increase considerably.

We cannot yet measure the impact of the CVI(W) being issued from optometry to prepare charities for a change in referral rates and patterns. This understanding will emerge as the CVIs are issued. It would be useful, however, to start data collection immediately now that the system has commenced in order that an evaluation is possible in the future.

Importantly, the CVI(W) now includes a new patient leaflet and, in the case of CVIs from the high street, is inclusive of macular-disease-specific information. In both cases, the patient is directed to WCB for impartial signposting via Perspectif. This decision was arrived at through agreement in the Wales Vision Forum.

## WHAT SUPPORT IS OUT THERE?

**Table 4.1**

Mapping Perspectif service categories to Visionary categories with initial count of instances in Perspectif.

<b>Visionary Categories</b>	<b>Perspectif Categories</b>	<b>Count</b>
Information, Advice and Guidance	<u>ADVICE   INFORMATION   HELPLINE</u>	24
Low Vision	LVSW Services within <u>WECS</u>	357*
Mental Health and Wellbeing	<u>COUNSELLING AND EMOTIONAL SUPPORT</u>	8
Rehabilitation	<u>REHABILITATION   SPECIALIST SOCIAL WORK</u>	32
Habilitation	<u>MOBILITY / HABILITATION</u>	12
Daily Living Skills	>see rehabilitation	--
Children/Young People/Families	>found manually	48
Employment	<u>EMPLOYMENT SUPPORT</u>	10
Vision Awareness Training	<u>TRAINING</u>	33
Advocacy	<u>ADVOCACY</u> => NO RESULTS	0
Residential Care/ Community Housing		0
Care at home		0
Retail /Charity Shop		0
Hospital based support/eye clinic liaison	<u>ECLOS/SIGHT LOSS ADVISERS</u>	20
Technology Services	<u>ACCESS TECHNOLOGY</u>	18
Welfare Benefits	<u>WELFARE BENEFITS ADVICE</u>	9
Resource centre	<u>RESOURCE CENTRE</u>	8
Mobile/outreach	> found manually	1
Befriending	<u>BEFRIENDING</u>	19
Sport	<u>SPORTS ARTS LEISURE AND HOLIDAYS</u>	49
Social activities	<u>CLUBS AND SOCIAL GROUPS</u>	62
Transcription service	<u>ACCESSIBLE MEDIA</u>	37

\*Represented by the accredited optometrists in Wales.



**Table 4.2** Perspectif categories not having a clear equivalent within Visionary list.

<u>EDUCATION</u> - not always 3rd sector	24
<u>FORUM / FOCUS GROUP</u>	7
<u>SUPPORT GROUP</u>	72
<u>TRANSPORT</u> - not always 3rd sector and underdeveloped in Perspectif	2 + 27*
<u>GRANTS</u>	12
<u>MEDICAL</u> - usually not 3rd sector	8
<u>DIRECT PAYMENTS   PERSONALISED BUDGETS</u> – Local Authority but often managed by Third Sector	34

\*Represented by an authority-by-authority service for Companion Travel Passes

Given the well-established routes into third sector support by LVSW and the likely increase in referrals from high street optometrists, it's important to see where services are available and where there are serious gaps.

### **The key signposting agencies.**

#### **Low Vision Service Wales.**

From the outset it is clear that there is excellent coverage from the Low Vision Service Wales, which is good, because they are one of the key referral routes as discussed above. In Wales, this is not a third sector service. We have evidence that there are gaps in the LVSW Domiciliary service. As more practitioners are enabled to offer the service we hope that more domiciliary services will appear. This is being monitored in the Low Vision Advisory Group chaired by WCB.

#### **Rehabilitation / Specialist Social Workers.**

Of the other key signposting agencies, Rehabilitation is a less consistent service and is the subject of WCB's survey on scarcity <https://wcb-ccd.org.uk/perspectif/library/115/addressing-a-workforce-crisis-in-wales>. Twenty of the twenty-two have at least one qualified VRS in post with an additional one commissioned ad hoc to a third sector partner, and another being a mobility officer, meaning that each local authority has some form of specialist sight loss worker.

VI Specialist Social Workers are still in operation in some authorities. Our review of these shows that only 3 out of 7 specialists still operate: Conwy, Swansea (plus a dual-sensory worker), Vale of Glamorgan.

There are significant waiting lists for rehabilitation in some areas of Wales. In many of these, there is a corresponding lack of commissioned third sector support to complement the VRS role. This is evident in Carmarthenshire, where the local society is inactive due to illness.

### **Habilitation.**

There are 11 services in local authorities and one from Guide Dogs. A report on the state of rehabilitation services in Wales is available at [http://wcb-ccd.org.uk/downloads/state\\_of\\_the\\_nation\\_children\\_\(FINAL\).docx](http://wcb-ccd.org.uk/downloads/state_of_the_nation_children_(FINAL).docx)

As a sector we are aware of a postcode lottery of habilitation services. We are working with Guide Dogs Cymru to try to secure funding for training from Welsh Government for VRS and habilitation specialists.

### **ECLOs.**

ECLO coverage is good throughout Wales with all health boards covered. However, with the increase in discharges from the high street (as opposed to the hospital) in cases of bilateral dry AMD, there is a potential gap in ECLO delivery. A pilot project is being explored to offer a primary-care-based eye care liaison officer to meet this demand. In order that there is no conflict with the signposting role that the optometrists already have, WCB must ensure that the community ECLO is conscious of that role and is in synergy with the optometrist. We have been commissioned by RNIB to work on a sight loss pathway for Wales and this presents an opportunity to establish protocols around the use of Perspectif.

Looking at the other areas in turn:

### **Advocacy.**

There is a conspicuous absence of advocacy services. These are crucial for obtaining the right level of welfare benefits through the appeals tribunal. WCB ran an excellent service up until around 2004, with almost 100% success rate. Since then, there has been no comparable service in Wales within the sight loss sector. While there are a number of welfare benefits advisors (see below), the lack of advocacy services is concerning when we know that the tribunals are designed to jeopardise

the chances of obtaining a higher level of benefits. Specialist advocacy with knowledge of sight loss and the traps that are set by tribunals is much needed, particularly in these times of economic hardship.

### **Children and Young People.**

It should be noted that this is not a category on Perspectif. The results were found manually.

#### School age.

There is a postcode lottery of services for CYPs. While each local education authority has some form of support for children of school age, there are gaps in support for specialist (VI) support. Also, some areas have services that include support outside the school, while others do not. For example, the SENCOM service is an example of best practice as it employs habilitation specialists that also work with children outside the school: i.e. at home and in the local environment. On the other hand, Merthyr does not provide specialist services in or out of the school. One family is considering moving 2 miles across the border to a neighbouring authority so that they can receive a service from SENCOM).

#### Pre-school.

A further problem is the lack of services and advice in the third sector for the parents of pre-school children. Any advice would be given on an ad hoc basis from organisations that work with children. Given the fact that early years development is critical for any child, this lack of provision has serious ongoing impact on a blind or partially sighted child.

Pre-school support is available through ALN teams in local authorities. However, the modes of referral are varied across authorities. In some, they come from the ophthalmology clinic, while others take referrals from any interested party including the parents.

#### Transitions.

This is covered by the RNIB Children, Young People and Families service.

### Charities.

There are a number of CYP organisations such as Look and UCAN as well as trust funds.

### **Resource centres.**

These are spread around Wales in the more densely populated areas: 6 are run by third sector services (one being a mobile resource) and 2 by local authorities. The Community Resource Bus is provided by Vision Support. Geography was found to be the biggest barrier to attendance at fixed resource centres, so the bus is a good additional service. We would recommend that this model be replicated in other areas, particularly where geography and transport are a problem, such as mid and west Wales.

### **Mobile / outreach.**

The only example being yielded through Perspectif is, again, the Community Information Bus run by Vision Support. Other forms of outreach include the tele-befriending schemes.

Because of the rurality of Wales, outreach and mobile services are crucial to ensure more isolated individuals can receive support.

### **Training.**

The figure seems quite good (33 instances) - there are 19 instances of awareness training services directed at organisations seeking to improve their support for individuals with sight loss. The remaining 14 are mostly directed at individuals. Some additional training options come from technology suppliers who might charge for training in the use of the products they sell.

This Perspectif category holds a mix of awareness training for non-disabled people and skills training for people with sight loss. It would be helpful within Perspectif to distinguish between these two broad strands for practical reasons.

Visual Awareness Training has often been controversial in the broader disability sector because of its tendency towards medical model thinking.

However, there are other models listed, notably Disability Wales' Disability Awareness Training.

### **Access technology.**

This is strongly represented by the technology manufacturers and distributors. They also deliver training, generally at a cost. Third sector support comes from RNIB, Care and Repair, and the Macular Society. RNIB is planning a technology products hub. It is likely that more support is available from the third sector, so this appears to be a gap in Perspectif to be addressed.

### **Retail / Charity Shop.**

Charity shops are not represented in Perspectif as they are merely fundraising channels. There are two known to us in Wales: one run by North Wales Society of the Blind and another by Sight Cymru, which also hosts a small resource centre.

### **Befriending.**

This is a service that smaller third sector organisations do very well. Typically, they run on a volunteer basis and take the form of telephone befriending. These services are well received by the most isolated people. It is often difficult to find the right volunteers, however.

In the larger societies there are face-to-face home visiting services such as those provided by Vision Support and Sight Life.

Befriending in general is provided by the whole sector: smaller charities, local charities with employees, and larger UK charities.

Covid opened up the possibility for smaller groups to continue peer-support sessions online; perhaps the majority were created from this opportunity. This includes an increase in condition-specific befriending and support.

### **Clubs and Social Groups.**

Another strong area for the societies – historically forming the traditional make-up of the 'blind societies' – are clubs and social groups. Covid impacted on these by pushing them online or closing them altogether,

but there are moves towards bringing these back face-to-face. There is good geographical coverage across Wales, although we are beginning to see clubs dropping off in West Wales, for instance, probably due to the lack of volunteers.

### **Support Groups.**

This Perspectif category attempts to differentiate between the social groups/clubs and groups that offer peer and organisation support on specific eye conditions.

This category, which doesn't seem to feature in the Visionary list, is well populated. Even if we take out the Macular Society groups (about 35 listed including other related entries), that leaves a sizeable number, 37, of groups giving support over a number of sight conditions and other criteria such as age. It was once said that there are too many sight loss charities. It is clear, however, that they are there to support a large number of specialisms. These groups are a credit to the organisations that host them, large and small, in that they are providing a rich tapestry of support to a variety of needs. A lot of this detailed support is best delivered by smaller specialist organisations, sometimes at a local level.

It is disappointing to see that there are no support groups for glaucoma in Wales – [Glaucoma UK](#) provides a handful in England and they offer an online group. Given the need for better awareness of taking drops for holding back glaucoma, it seems that groups with the possibility of advisory visits from medics would reduce the risk of deterioration. [Retina UK](#) has established a group in North Wales but is struggling to do so in the south, probably because of the difficulty in securing volunteers.

### **Welfare Benefits Advice.**

This form of advice is essential for ensuring people are gaining the full range of financial support due to them. The range of support evidenced by Perspectif is disappointing. There are three online services for calculating benefits and four offering a personal service.

An example of the problem of short-term funding from, for instance, the Lottery is provided by the RNIB RAISE project. This service was highly valued by rehabilitation officers and others and its termination was unwelcome. It is important that people with sight loss get access to

specialist knowledge on the subject of benefits. Some support comes from Citizens' Advice, but the specialist knowledge is important.

### **Accessible Media.**

This category in Perspectif is a mix of transcription services, libraries, support services for theatre and cinema and talking newspapers. For the present purpose six transcription services are listed which are generally charged-for services. These services are sometimes income-generators related to contracts with utilities providers and the like.

Local Societies have the technology to produce audio and braille and they will use this to produce their own materials for members in an accessible form. However, the production of, say, a book chosen by the individual is not normally carried out free of charge. An RNIB Service (not listed in Perspectif) called Free Personal Transcription allows service users to have a limited amount of transcription carried out free of charge. At WCB we have experienced a significant downturn in the numbers of people requesting audio given that digital devices will more accessibly read from a file or webpage. We rarely get a request for braille.

Historically, some social services departments had braille machines but we have not yet reviewed the status of this.

### **Employment Support**

Apart from the Access to Work service, a TPT internship scheme called 'Get Set Progress', and a workplace assessment service, this category holds records mainly for mentoring support in a broad sense. The JobSense/ELITE employment advice programme is widely distributed through Wales.

With 1 in 4 VI people of working age out of employment, more services are needed with an understanding of sight loss that enable and empower people to gain employment. Services such as TPT's 'Get Set Progress' and JobSense/ELITE prepare the employee while RNIB's Employment Support programme can provide help during employment.

## **Counselling and Emotional Support.**

Three of the four major regional societies offer some form of counselling or emotional support. In addition, Macular Society, RNIB, and Deafblind UK offer a service nationally. Children and families are also supported through the North Wales Society of the Blind and the Royal Society for Blind Children.

Anecdotally, the RNIB service has a long waiting list. The Macular Society (obviously aimed at people with a macular condition) has a short waiting list.

The Low Vision Service Wales has included questions within their Low Vision Assessments that might trigger a referral to the GP for a mental health referral, with the patient's consent. We are hoping to gather some statistics on the prevalence of such referrals.

## **Sports arts, leisure, and holidays.**

There is a good number of sports activities available thanks to the regional societies. In addition, UK-wide services offer support to groups nationally (such as Welsh Association of VI Bowlers). The Disability Sports Development Officers at Disability Sport Wales work to develop opportunities throughout Wales.

## **Advice / Information / Helpline.**

All of the above depends to some extent on the quality of information and advice coming from the larger charities. People need to be directed to services and organisations need to be generous in the way they signpost individuals to other organisations for support. There are 24 helplines listed in *Perspectif*: some are condition-specific, such as Behçet's UK Helpline, and others are related to other criteria such as age (Age Cymru Advice Line, SNAP Cymru Helpline). Sightline, a generic sight loss helpline is offered by RNIB (not listed in *Perspectif* currently).

*Perspectif* holds 8 advice services. This is a more focused and committed service than an information service where there is a relationship with the service user that might require knowledge of personal information. Again, the kinds of advice services cover conditions, financial advice, and education. This category could no doubt be expanded.



Information as a category is filled with a large number of library services, if only because they offer an inroad into the local authority information hubs that are often sited at public libraries. There are also on-line resources such as Guide Dogs' Starting Point and the My Macular and Me webinars.

### **Transport.**

This category needs expansion. We have added the paths to concessionary travel for each local authority, but more needs to be added in the area of community transport and overseas travel. Sight Life offers their Transcall service. We imagine there are other examples of this kind of local support available.

## CASE STUDIES

We felt, for the purposes of this study, it would be helpful to move away from a theoretical analysis of the data and actually take a more applied approach. Therefore, we chose 9 postcodes in Wales to see what support there would be for people with a certain profile (see Table 1). It must be remembered that the data in terms of available support is limited by:

- a) whichever services are listed in Perspectif AND
- b) the accuracy of our categorisation of these services AND
- c) the generality of the local authority as the boundary for coverage (e.g. in Powys, services may not cover the whole of this large county).

Indeed, a useful by-product of this survey is to identify gaps in provision, both in real terms and in terms of Perspectif's data, and structural limitations of the database.

Method:

- 1) Find 9 different postcodes to reflect the different areas of Wales (see Geography of Wales above)
- 2) Apply a search on Perspectif for services and support for a specific personal profile. We chose the profile as created for the training module for LVSW practitioners. This would help to identify gaps that would be useful for the development of services that LVSW can refer to.
- 3) See if the gaps are a result of Perspectif either not having the services listed or not categorising accurately.
- 4) See if the services are being delivered outside the third sector.
- 5) Plug the gaps where you can.
- 6) Make a comparison between areas and between the WIMD rankings and the Perspectif results.
- 7) Draw some conclusions.

### Individual profile for 9 case studies.

*The person (aged 55) lives alone and has developed Dry AMD and lost a considerable part of their central vision in both eyes. They work as a receptionist in a law firm. They are worried that they will lose their job. When their sight was better they enjoyed playing bowls and would socialise a lot in pubs. Now they find it hard to get out and about, finding*

*public transport challenging. They are struggling to cope with the consequences of their sight loss and is at risk of social isolation.*

From this case study we identified a number of search goals:

- 1) I would want to know more about my condition.
- 2) I want help with mobility and getting around.
- 3) I would want help with retaining employment.
- 4) I would look for benefits and concessions such as travel concessions.
- 5) I would look for support for people over 55.
- 6) I would like to continue with sports – notably bowls.
- 7) I would like to connect with my local society to volunteer.
- 8) I feel I would benefit from emotional support.
- 9) I would like help with accessing technology such as my phone and computer.
- 10) I would like to meet other people who understand my sight loss.

Next we mapped these goals against service categories:

**Table 5: Perspectif categories chosen to address search goals**

<b>Goal</b>	<b>Visionary Categories</b>	<b>Perspectif</b>
I would want to know more about my condition.	Information, Advice and Guidance	Advice. Information. Helpline.
I want help with mobility and getting around.	Rehabilitation	Rehabilitation
I would want help with retaining employment.	Employment	Employment support
I would look for benefits and concessions such as travel concessions.	Welfare Benefits	Welfare Benefits Advice
I would look for support for people over 55.	Information, Advice and Guidance	Advice. Information. Helpline.
I would like to continue with sports – notably bowls.	Sport	Sports Arts Leisure and Holidays
I would like to connect with my local society to volunteer.	Information, Advice and Guidance	Advice. Information. Helpline.
I feel I would benefit from emotional support.	Mental Health and Wellbeing	Counselling and Emotional Support
I would like help with accessing technology such as my phone and computer.	Technology Services	Access Technology
I would like to meet other people who understand my sight loss.	Befriending	Support groups. Befriending.

Taking this set of goals, we first entered into Perspectif the postcode, local authority, and Service Type in turn. (See Table 6.1 below)

Secondly, we performed the same searches but, where no viable service was identified, we looked at the ‘other results’ that appear below the main results where available. (Table 6.1)

Thirdly, we conducted a free word search for any goals remaining that had not been met by the above searches. (Table 6.2)

## **Evaluation of case studies.**

First of all, it is essential to note that the findings are a reflection of Perspectif's content and structure, rather than a full survey of the services available. There may be others that have not emerged either through discussion with our members or because of limitations in the categorisation.

On the positive side, it was good that all goals were met through the above search sequence within Perspectif. (Table 6.3). We say 'met' to the extent that at least one signposting opportunity emerged from the search. Whether the needs are met is another matter. What was disappointing was the limited range of relevant services coming from smaller, local organisations – disappointing because WCB, as the umbrella body for sight loss charities in Wales, would like to see a strong, community-based support network. We know that one exists in some form, but perhaps we are too ambitious in what to expect from it, and that, generally, only the larger UK charities are resourced to deliver the kind of support that is needed in areas such as mental health and employment support, particularly as these are areas demanding the resources needed to work in collaboration with other providers from related sectors – only larger organisations are in a position to commit themselves to working relationships that have contractual constraints and demands. The downside of this is that services become expensive to deliver and may only make limited use of volunteer support delivered locally through a constellation of unrelated small charities. In a related way, a large proportion of the second stage search results are national (UK or Welsh) organisations and ones which are not specifically sight loss orgs.

There is some merit in the larger organisations functioning as signposting agencies to a full spectrum of support at local and national levels. The third sector and related services in the other sectors form a complex map and there is no possibility of homogenising the variety of modes of delivery and individual perspectives each organisation takes on the problems being addressed. Nor need there be. While what we call the postcode lottery may seem undesirable at the level of equality of access, it is not necessarily desirable to even out provision to create homogeneity, since we should also be mindful of delivering to local needs in a way that is appropriate to the locality. Therefore, a better solution might come from offering signposting centrally from a knowledgeable organisation that has no reason merely to refer individuals inwards towards their own services. This solution is being

recognised in Wales now that Perspectif is being included in the pathway leading from the Low Vision Service Wales. This is in its early stages but is slowly gaining momentum at an organisational strategic level. Perspectif must develop more tools for the user (such as a local health board-specific pathway through the database) and broaden its range of services to the extent that anyone, anywhere in Wales will find something to support their needs.

Where a larger organisation (Macular Society providing the leading example in our case study) is in a position to signpost, this is not incompatible with Perspectif being a tool to signpost people to the organisation in the first instance. This is more than simply a cascading model since Perspectif will also branch around the organisation so to speak, offering other choices and opportunities that may run parallel with those the specialist organisation might offer or direct people towards. Given the emphasis on 'waiting well' - a keyword in support services in health currently - it seems perfectly appropriate to ensure people are directed *somewhere* as soon as possible in this way, particularly in a time-critical situation. Support of the humblest kind might be sufficient to reduce anxiety, social isolation and so on, simply by putting someone in touch with people who have shared experiences. Fortunately, in our case study examples, there is an abundance of peer support in the form of the Macular Groups. By connecting with people with shared experiences there is a strong likelihood that a 'trickle-up' model could be happening (if I may be permitted to invert that term) such that a new group member might pick up tips at the community level and be made aware of support from 'higher' up. It seems to us that the Macular Society has understood this and has mobilised its volunteers towards this model of support.

Given that most support was being provided from UK-wide services or, as with the case of the VRS, there is a fairly even coverage across Wales, the operation of a postcode lottery is not as evident as one would expect. At the level of face-to-face social and activity-based groups delivered by local societies the postcode lottery ought to be felt more strongly (the overall service counts are noticeably lower across mid-Wales). However, since online and virtual support via telephones was ramped up in the wake of Covid, even the social groups have been better serving the rural areas. One might speculate that a greater sense of community responsibility brought out through the pandemic has

meant that ground-level support has become everyone's responsibility, in a manner of speaking, resulting in more initiatives being delivered on an ad hoc basis. It would be interesting to investigate these.

In these examples where macular disease is the common factor, it is clear that a key agency is the Macular Society: it provides information about the condition; emotional/counselling support; and peer support. The information line would almost certainly direct people to advice on managing finances and so on. A similar search over other conditions would be useful as a comparison since, for example, there is little support in Wales from Glaucoma UK.

A surprise service that fits neatly into the work area of our hypothetical service user is the Support and Mentoring service from the Society of VI Lawyers. We would ask two questions: what is the quality and depth of this support – does it reach to clerical staff, for instance? And, more generally, what support is out there for other professions?

Regarding employment generally, for people already in employment it is helpful that a combination of the RNIB Employment Support service and the Government Access to Work service should provide the client with good support. Again, however, there is little in the way of support from local charities.

## GENERAL CONCLUSIONS AND RECOMMENDATIONS

Covid played a significant role in moving services to online and telephone delivery. While this has made services much more available to more people, it doesn't address the need for social interaction that many people have. This is a significant issue as social isolation is a risk here. Thankfully, many local societies and clubs have reinstated face-to-face social events and this is where the smaller local organisations show their strength against the larger UK organisations. However, some organisations are finding it difficult to recruit volunteers to run face-to-face groups.

Our case studies highlighted the prevalence of Macular groups throughout Wales. There are a number of local societies who have merged their groups with Macular Groups, which is a good development as it shows collaborative working. However, many of these groups are Lottery funded and when this short term funding comes to an end, there will be a significant impact on the future of these groups if they are not able to be self-sustaining.

Regional Societies (notably the big four in Wales) are able to deliver some critical support alongside their clubs and resource centres. Being tied in with the rehabilitation service in their area enables them to be well connected with service users and able to plug the gaps in the VRS' role. In Wales, however, this coverage thins out in West and Mid Wales.

**Mobile resource centres - along the lines of the bus operated by Vision Support - would be an excellent model for improving support in those areas.**

We note that there is an absence of advocacy services within the sight loss sector. While these may be available in other sectors, we feel that the specialist knowledge of sight loss is essential for securing successful results at tribunals, where it is known that traps are deliberately set to trick the claimant.

The Sight Loss Pathway is a concept being explored in the UK generally and specifically in Wales since it would require its own variant. WCB shall be facilitating a consultation on this shortly, taking in the views of the membership and individuals with sight loss. In the draft version we have seen, there is a very generalised view of third sector support with all the detail being devoted to the NHS provision within the pathway. Indeed, the third sector section has no detail as to specific services. Through Perspectif, we hope to be representing the role played by the



Third Sector in the proposed pathway more fully. As a practical support, **we would envisage creating pathways through Perspectif based on Local Health Boards' individual requirements.** (We note that one health board in England has expressed an unwillingness to adopt a one-size-fits-all pathway). We are working with Swansea Bay UHB to see how the third sector might be signposted to in that authority. **We would like to form regional groups (such as the proposed Sight Loss Council) who can suggest the shape of the pathway in their LHB area.**

The boundaries between sectors need to be broken down somewhat. For instance, mental health support can be provided in many quarters from outside the sight loss sector. Perspectif does not recognise boundaries of this sort so **we must explore those possibilities so that support is more widely available, and people are not limited by the relative strengths of the sight loss charities.** Services for older people generally provide an example of a useful path towards a broader range of support.

**WCB would like to recruit 22 volunteers with sight loss** who are aware of the services in their local authority and can inform WCB of changes and development in their areas. We would need to explore funding options to recruit and manage a volunteer coordinator and to provide the necessary technical support.

WCB's role is to strengthen knowledge of our member organisations' respective roles in the sector. Perspectif and its associated information services, along with regular meetings of the Wales Vision Forum, have gone a long way during Covid and since to improve awareness of these services. Through Perspectif, we want to create a situation where people with sight loss and workers in the sector have no excuse not to have this awareness. **We would like them to use Perspectif in order to offer a wide range of choice for people with sight loss.**

**Table 6.1:** Number of services resulting from the hard search method (A= top results, B=other results)

	LL13 7RH		LL28 5TG		LL16 5HG		SY23 3AR		SY16 3EL		SY18 6DX		CF24 0BL		CF71 7AF		SA67 8UH	
	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B
<b>Perspectif category</b>																		
1) Advice.	1	x	1	x	1	x	0	0	0	0	0	0	0	0	0	0	0	0
Information.	2	x	2	x	2	x	1	x	1	x	1	x	1	x	1	x	1	x
Helpline.	0	16	0	16	0	16	0	16	0	16	0	16	0	16	0	16	0	16
2) Rehabilitation	2	x	2	x	2	x	1	x	1	x	1	x	2	x	2	x	1	x
3) Employment support	0	9	0	9	0	9	0	9	0	9	0	9	1	x	1	x	0	9
4) Welfare Benefits Advice	0	8	0	8	0	8	0	8	0	8	0	8	0	8	0	8	0	8
5) Advice.	1	x	1	x	1	x	0	0	0	0	0	0	0	0	0	0	0	0
Information.	2	x	2	x	2	x	1	x	1	x	1	x	1	x	1	x	1	x
Helpline.	0	16	0	16	0	16	0	16	0	16	0	16	0	16	0	16	0	16
6) Sports Arts Leisure and Holidays	2	x	2	x	2	x	0	23	0	23	0	23	6	x	2	x	0	x
7) Counselling and Emotional Support	1	x	2	x	2	x	1	x	0	5	0	5	0	5	0	5	0	5
8) Access Technology	0	18	0	18	0	18	0	18	0	18	0	18	0	18	0	18	0	18
9) Support groups.	1	x	2	x	2	x	2	x	3	x	3	x	4	x	2	x	3	x
10) Befriending.	3	x	3	x	3	x	2	x	2	x	2	x	2	x	3	x	1	x

x = met by search A

**Table 6.2** Number of services resulting from keyword search (not limited by location)

<b>Goal</b>	<b>Keywords relating to goal</b>	<b>No. results</b>
Advice on condition	macular; amd;	42
Help with mobility	daily living; independence;	25
Employment	job retention; work; jobs;	80
Benefits Advice	benefits; concessions;	17
Help for over-55s	over 55; older people;	2
Sports / bowls	sports; bowls;	5
Emotional Support	mental health; mental wellbeing;	5
Help with Technology	iphone; computer training;	1
Connecting with people	peer support;	5

**Table 6.3** The most suitable services identified through the above search methods (combined across methods and locations)

<b>Goal</b>	<b>Visionary Categories</b>	<b>Perspectif</b>	<b>Notable services</b>
1) I would want to know more about my condition.	Information, Advice and Guidance	Advice. Information. Helpline.	Macular Society Helpline / <u>Advice and Info Line</u>
2) I want help with mobility and getting around.	Rehabilitation	Rehabilitation	The <u>VRS for the local authority</u>
3) I would want help with retaining employment.	Employment	Employment support	<u>Work on Wellbeing</u> Access to Work RNIB Employment Support Support and Mentoring Society of VI Lawyers
4) I would look for benefits and concessions such as travel concessions.	Welfare Benefits	Welfare Benefits Advice	<u>Citizens Advice Welfare Rights Advice</u> <u>Financial Wellbeing Service</u> (Vision Support)
5) I would look for support for people over 55.	Information, Advice and Guidance	Advice. Information. Helpline.	<u>Age Cymru Advice Line</u>
6) I would like to continue with sports – notably bowls.	Sport	Sports Arts Leisure and Holidays	Welsh Association of VI Bowlers <u>Find a Sport</u> (Deloitte Parasport)

7) I would like to connect with my local society to volunteer.	Information, Advice and Guidance	Advice. Information. Helpline.	Macular Society Helpline / Advice and Info Line
8) I feel I would benefit from emotional support.	Mental Health and Wellbeing	Counselling and Emotional Support	Vision Support <u>Counselling Service</u> Sight Cymru <u>Counselling and Emotional Support</u> Macular Society <u>Counselling Local Minds (Mind)</u>
9) I would like help with accessing technology such as my phone and computer.	Technology Services	Access Technology	<u>Working Age Connect by Tech</u> (Macular Society)
10) I would like to meet other people who understand my sight loss.	Befriending	Support groups. Befriending.	<u>Let's Talk Befriending Service</u> (Vision Support) <u>Home Visitor service (VS)</u> Ceredigion Assn. <u>Telephone Support</u> VI Brecon <u>Telephone Support</u> Sight Life <u>Befriending</u> Sight Cymru <u>Ringaround</u>